Regional Lynch Syndrome Expert Network

North Thames
NHS Genomic Medicine Service Alliance

First and foremost...

Welcome to our 1st edition of expert network newsletter. In this newsletter you get the most updated information about the expert network, the services of the network, educational and research trial updates.

If any of the information is incorrect, needs updating or you have additional information, Please contact Amal Joe Tharayathu, the expert network coordinator, lnwh-tr.lynchsyndrometeam@nhs.net

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Top news

Regional Expert network meeting was organised on 22nd Mar 2024. Please check the following page for more info.

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In this newsletter you will find:

3rd Expert network meeting, List of services of the network, contact information etc. Keep Reading! ↓

3rd LYNCH SYNDROME EXPERT NETWORK MEETING 22nd Mar 2024

NORTH THAMES GMSA

✦

10 MAY 2024

Regional Lynch Syndrome Expert Network

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The third regional lynch syndrome expert network meeting of the North Thames GMSA was organized on 22nd March 2024. This time it was a virtual event that attracted various attendees.

The meeting started with a warm welcome and an update on the project progress provided by Dr Kevin Monahan, Consultant Gastroenterologist, Lynch Syndrome Clinic, St Mark's Centre for Familial Intestinal Cancer. Kevin briefed about the services and contact information on the North Thames GMSA website.

Next we had an update on the Mainstreaming training provided in the North Thames GMSA by Anna Koziel, Regional Lynch Syndrome nurse for the North Thames GMSA.

Followed by a presentation from Laura Monje Garcia, The National Lead Nurse for the Lynch Syndrome Project. Laura discussed the information resources and an update from the UCLH Surveillance hub.

Alice Coulson, Principal Genetic Counsellor, North-east Thames clinical genetics services presented an update on the Gosh clinical genetic service at the region. The slides provided an overview on the services, referral tips, patient pathway and contact information.

Vicky Cuthill, - Nurse Consultant, The St Mark's Centre for Familial Intestinal Cancer presented on the Life-long care for people with an inherited predisposition to colorectal cancer.

The final presentation was given by Ashwin Kalra, Clinical Research Fellow in Gynaecological Oncology Barts Health NHS Trust who provided an update on DETECT 2 study.

The information about the expert network and services offered are listed on the website: https://norththamesgenomics.nhs.uk/our-work/transformation-projects-and-core-activities/national-transformation-project-lynch-syndrome/

If you would like a copy of the presentation please contact us by email.

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lnwh-tr.lynchsyndrometeam@nhs.net

FORUMS/ MDT MEETING TO DISCUSS MAINSTREAMING AND COMPLEX CASES

1.

ST MARK'S HOSPITAL: CENTRE FOR FAMILIAL INTESTINAL CANCER – VIRTUAL HEREDITARY CANCER MDT

Held every Tuesday 9.00 am to 10.00 am to discuss mainstreaming, complex diagnostic or surveillance queries and other aspects of hereditary cancer. Referrals from across SE England aimed to link separate specialist services.

If you would like to attend this meeting or present a case, you can email LNWH-tr.SMCFIC@nhs.net for the Microsoft Teams access details.
If you would like to present a case, please email this proforma to LNWH-tr.SMCFIC@nhs.net Virtual Hereditary Colorectal Cancer MDT proforma

2.

LONDON VIRTUAL GYNAE RISK-REDUCING SURGERY MDT – UCLH AND BARTS

It discusses all women with Lynch Syndrome considering risk-reducing gynae surgery. These cases must be approved by the MDT prior to surgery. In addition unusual external cases are discussed where expertise is required e.g. those with prior radiotherapy for bowel cancer or those requesting surgery at an unusually young age.
If you would like to attend this meeting or present a case, you can email sophia.mekoma@nhs.net for the Microsoft Teams access details.

This Virtual MDT involves the UCLH and Barts gynae risk reducing surgery teams and the North-east Thames, North-west Thames and the Royal Marsden clinical genetics teams.

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3. GYNAE-ONC MDTS AT UCLH AND BARTS.

This virtual MDT involves UCLH and BARTS gynae-oncology teams.
Patients with suspected gynaecological cancer can be referred for MDT review.
Please use the below email for proforma.

Date of MDT:Every Tuesday
Time: 15:15
Location: 4th floor Macmillan Cancer Centre
Contact email: ucl-tr.GynaeOncology@nhs.net

CLINICAL GENETIC SERVICES

1. NORTH-WEST THAMES REGIONAL GENETICS SERVICE

Lead Consultant: Bianca DeSouza
Lead Genetic Counsellor:
Cheryl Berlin
Referrals to:
lnwh-tr.geneticreferrals@nhs.net
Clinical enquiries:
lnwh-tr.nwtrgscancerqueries@nhs.net
Supporting Website:
https://www.lnwh.nhs.uk/genetics

2. NORTH-EAST THAMES REGIONAL GENETICS SERVICE

Based at Great Ormond Street Hospital (covers pediatric and adult patients)
Lead Consultant: Dr Munaza Ahmed
Lead Consultant for Cancer Genetics:
Dr V K Ajith Kumar
Lead Genetic Counsellor for Cancer Genetics:
Ms. Alice Coulson
Referrals to:
gos-tr.ClinicalGenetics@nhs.net
Clinical enquiries:
gos-tr.ClinicalGenetics@nhs.net
Supporting Website:
About the Clinical Genetics department | Great Ormond Street Hospital (gosh.nhs.uk)

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3. CANCER GENETICS UNIT AT RMH

Royal Marsden Hospital Cancer Genetic Unit
Lead Consultant:
Terri McVeigh

Referrals to:
rmh-tr.cancergenetics@nhs.net

Clinical enquiries:
rmh-tr.cancergenetics@nhs.net

Supporting Website:
https://www.royalmarsden.nhs.uk/our-consultants-units-and-wards/clinical-units/cancer-genetics-unit

CLINICAL SERVICES; (FOR LIFELONG CARE)

1. THE ST MARKS CENTRE FOR FAMILIAL INTESTINAL CANCER (SMCFIC), ST MARK'S: THE NATIONAL BOWEL HOSPITAL (NATIONAL LEAD CENTRE)

The Lynch Syndrome Clinic at St Mark's, the National Bowel Hospital, looks after patients with Lynch Syndrome. The focus of this service is to provide people and families with this condition with lifelong multidisciplinary holistic care with the aim of early diagnosis and prevention of cancer and support for psychological and other health needs. We work within the Family Cancer Clinic, and closely with colleagues in the Polyposis Registry. We see people from both from our local geographical region and also from elsewhere in the United Kingdom.

Lynch Syndrome (SMCFIC) Service
Lead Consultants:
Dr Kevin Monahan (Clinical Director for Lynch Syndrome and Family Cancer Clinic)
Dr Andrew Latchford (Clinical Director for Polyposis Registry)
Consultants:
Mr Ashish Sinha, Prof Huw Thomas, Prof Omar Faiz
Lead Nurse:
Vicky Cuthill
CNS practitioners:
Menna Hawkins, Anna Koziel, Laura Monje-Garcia, Cherryl Cabalit, James Cockburn,
Referrals to:
lnwh-tr.smcficreferrals@nhs.net
General enquiries:
lnwh-tr.smcfic@nhs.net
Supporting Website:
http://www.stmarkshospital.nhs.uk/the-lynch-syndrome-clinic/ The Lynch Syndrome Clinic - St Mark's The National Bowel Hospital (stmarkshospital.nhs.uk)

2. GYNAECOLOGY SERVICES @ BARTS HEALTH

Women's Precision Prevention Clinic (WPP)
Lead Consultant:
Professor Ranjit Manchanda
CNS:
Ms. Guida Kurzer, Miss Rachel Perfect
Referrals to:
bartshealth.gynaeoncadminrlh@nhs.net (and CC CNS team)
Clinical enquiries:
bartshealth.wpp.cns@nhs.net
Supporting Website:
Home - Barts Health NHS Trust

3. NCL LYNCH SYNDROME SURVEILLANCE AND RISK-REDUCING SURGERY HUB AT UCLH

This hub is accessed by patients with confirmed Lynch Syndrome. The services offered include weekly clinics (colorectal and familial gynae cancer), ongoing cancer surveillance (colonoscopy, transvaginal ultrasound scans, CA125 blood tests and hysteroscopy with endometrial biopsy) and risk-reducing surgery (hysterectomy and bilateral salpingo-oophorectomy). The team also provides support to patients outside of clinic consultations through a patient helpline and email.

Lynch Syndrome services at UCLH
Lead Consultants:
Dr Roser Vega (Gastroenterology) and Prof. Adam Rosenthal (Gynecology)
CNS:
Helen Francis - Lead CNS (uclh.gilynch@nhs.net)
Referrals to:
E-Referrals/ERS Dr Roser Vega for colorectal risk and Prof Adam Rosenthal at UCLH for gynecological risk
Clinical enquiries:
uclh.gilynch@nhs.net
Supporting Website:
https://www.nclcanceralliance.nhs.uk/our-work/diagnosis-and-treatment/lynch-syndrome/

SPECIALIST SERVICES;

1. SKIN/ADNEXAL CANCERS IN LYNCH SYNDROME

RMH Dermatogenetics
Lead Consultant:
Terri McVeigh/Kara Heelan
Referrals to:
CANCERGENETICS (THE ROYAL MARSDEN NHS FOUNDATION TRUST - RPY) rmh-tr.cancergenetics@nhs.net
Clinical enquiries:
CANCERGENETICS (THE ROYAL MARSDEN NHS FOUNDATION TRUST - RPY) rmh-tr.cancergenetics@nhs.net
Supporting Website:
https://www.royalmarsden.nhs.uk/our-consultants-units-and-wards/clinical-units/cancer-genetics-unit

2. UROLOGY LYNCH SYNDROME SERVICE

Lead Consultant:
Prof Rakesh Heer
CNS:
Ana Peterkin
Referrals to:
Prof Rakesh Heer
Clinical enquiries:
r.heer@imperial.ac.uk
Supporting Website:
https://www.imperial.nhs.uk/consultant-directory/rakesh-heer

3. GYNAECOLOGY SERVICES @ BARTS HEALTH

Women's Precision Prevention Clinic (WPP)
Lead Consultant:
Professor Ranjit Manchanda
CNS:
Ms. Guida Kurzer, Miss Rachel Perfect
Referrals to:
bartshealth.gynaeoncadminrlh@nhs.net (and CC CNS team)
Clinical enquiries:
bartshealth.wpp.cns@nhs.net
Supporting Website:
Home - Barts Health NHS Trust

4. UCLH MENOPAUSE TEAM

Referrals should be made to uclh.rmu@nhs.net

Further enquiries:
zachary.nash@nhs.net

UCLH Gynae management at UCLH offers menopause services.

Eligibility Criteria:
- Surgical menopause before the age of 40 (premature ovarian insufficiency)
- Those reluctant to have, or declining, risk reducing surgery due to concern about menopausal symptoms.
- Those where there is uncertainty about suitability for HRT or contra indications to HRT.
- Those with significant ongoing menopausal symptoms despite 3 months of adequate oestrogen HRT.

EDUCATIONAL RESOURCES

MAINSTREAMING WORKSHOPS FOR LYNCH SYNDROME

1.

Following the completion of RMP online modules, members of Colorectal and Endometrial MDTs (CNSs, Medical Oncologists and Surgeons) could undertake further mainstreaming workshops provided by the Regional Lynch Syndrome Nurse in preparation of undertaking mainstreaming for genetic testing for Lynch syndrome of eligible patients.

Mainstreaming workshops consist of bespoke tutorials delivered to the teams in a format of five 2- hourly sessions delivered every 2 weeks. However, they can be tailored to the individual teams needs and additional sessions can be added as required.

These bespoke tutorials aim to provide the training needed to support with the theoretical and practical aspects of obtaining informed consent and genetic counselling and testing for Lynch syndrome. During the workshops, participants will have the opportunity to practice genetic counselling consultation for LS together with exploring various scenarios of challenging situations. Guidance and support are provided on how to overcome those challenges and provide solutions.

Ongoing support is provided upon completion of the mainstreaming workshops together with practical support in setting up the service within the local teams.

For further information about the workshops please contact
Lynch Syndrome Team at St Marks Hospital
lnwh-tr.lynchsyndrometeam@nhs.net

2. MAINSTREAMING GENOMIC MEDICINE

To discuss you/your team's needs, please contact nt-gmsa@gosh.nhs.uk

The mainstreaming training is not only for Lynch, it's for any cancer predisposition and other genetic condition

Click on the link for the event.

- Mainstreaming genomic medicine half day training sessions: Genetic testing: how to request this for your patients.
- Provides a practical toolkit for heath care professionals to request genetic testing including:
  1. the use of the National Genomic Test Directory
  2. key points to cover during conversations with patients.
  3. consenting of patients of genomic testing
  4. communicating genetic test results.
- Previous sessions held every 3 months.
- Next session June 2024

3. GENOMICS QUESTION TIME MONTHLY DROP-IN SESSIONS

Genomics Question Time is also an opportunity for healthcare professionals to ask questions about the National Genomic Test Directory and the April 2023 directory update.

If you have any questions about the sessions, please contact norththamesglh@nhs.net

The North Thames GMSA is running monthly drop-in sessions to provide an opportunity for healthcare professionals to ask questions about Whole Genome Sequencing and mainstreaming of genomic medicine. These sessions are held on the first Thursday of every month, 12:30pm to 1pm.

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LYNCH SYNDROME MAINSTREAMING GENETIC TESTING AT ENDOMETRIAL CANCER DIAGNOSIS

4.

This training package has been developed specifically for members of gynaecology and gynae-oncology multidisciplinary teams (doctors, nurses, AHPs of all grades) and consists of three interactive modules. It takes approximately one hour to complete all three modules.

This has undergone a robust development process with input on content and design from cancer clinicians, geneticists, genetic counsellors, clinical nurse specialists and researchers. You have contributed to this development process and we are very grateful for your support with this.

This is now freely accessible on The (NHS) Learning Hub (formerly e-Learning for Healthcare). We have worked with the NHS e-learning for Healthcare team programmers in developing this, in order to make this freely available through the same access point colleagues use to complete their regular mandatory training.

GIn line with NICE diagnostic guidance DG42 as well as other national and international guidelines recommending Lynch syndrome testing for all women with endometrial cancer, implementation has begun by gynaecological oncology teams through mainstreaming pathways. However, implementation is still very patchy and there remains a huge need to improve awareness and skills of colleagues (including general gynaecology teams) to deliver and implement this.

There is certification available for staff members who complete each of the three modules.

We are also in the process of making the programme available (free of cost) on 'e-Integrity' which is the corresponding international platform for international colleagues enabling broader dissemination for community benefit.

Contact: a.kalra@qmul.ac.uk>

See link- https://learninghub.nhs.uk/catalogue/ec-lynch-testing

OTHER RELEVANT NETWORKS; (RDCN AND POLYPOSIS)

1. HEREDITARY GASTROINTESTINAL POLYPOSIS SYNDROMES- RARE DISEASE COLLABORATIVE NETWORK (RDCN)

A RDCN is a 'recognized network of member providers, each of which has a demonstrable research-active interest in a rare/very rare disease, the aim of the network being to improve patient outcomes.' The network is composed of rare disease collaborative centres (RDCC). A centre is a provider that has been recognized as having demonstrable research-active interest and works with other recognized providers in the network to improve patient outcomes for the rare/very rare conditions.
Please see the below link to the RDCN consensus statement: Hereditary gastrointestinal polyposis syndromes Rare Disease Collaborative Network consensus statement agreed at the RDCN meeting Birmingham 17th February 2022 | BJC Reports (nature.com

The RDCN for polyposis syndromes covers:
- Familial adenomatous polyposis
- MutYH-associated polyposis
- Polymerase proofreading associated polyposis
- Peutz-Jeghers syndrome
- Juvenile polyposis syndrome
- Other ultra-rare Mendelian polyposis syndromes

Please note serrated polyposis syndrome is not considered a rare disease and is therefore not part of this network. Patients can be cared for locally adhering to current BSG guidelines for colonoscopic surveillance.

Rare Disease Collaborative Centres and Network
The following centres are now recognized by NHSE:
- Birmingham
- Edinburgh
- Manchester
- St Mark's Hospital, London
- Cardiff
- Southampton
- South-West/Peninsula

In order to be recognized as a RDCC, each centre should demonstrate compliance with commitment 24 of the UK Strategy for Rare Diseases:

- Has a sufficient caseload to build recognised expertise
- Service does not rely on a single clinician
- Co-ordinates care
- Arranges for co-ordinated transition from children's to adult services
- Involves people with the rare disease, and their families and carers
- Supports research activity

Principles of clinical care
Patients and families with an hereditary gastrointestinal polyposis syndrome need lifelong care and support, with personalised key clinical decisions including around:

· Type and timing of colorectal surgery to prevent bowel cancer
· Intestinal endoscopic surveillance programmes according to disease severity and underlying genetic cause of disease
· Requirement for extra-intestinal surveillance. Patients with these conditions require lifelong care
· Cascade genetic testing and surveillance of family members
· Family planning/pre-implantation genetic diagnosis

Network Contact details

Centre
Contact details for referral

Edinburgh
Farhat.Din@nhslothian.scot.nhs.uk

Cardiff
Polyposis.colorectal.CAV@wales.nhs.uk

Manchester
mft.manchesterpolyposis@nhs.net

Birmingham
Genetics – wmfacs@nhs.net
Adults – andrewbeggs@nhs.net
Children – ronald.bremner@nhs.net

London
LNWH – tr.smcfic@nhs.net

Southampton
uhs.polyposisteam@uhs.nhs.uk

Exeter/Plymouth
rduh.lynch-polyposis@nhs.net

Clinicians should refer any patient with polyposis to their relevant local RDCC. Until sufficient resource has been established within the RDCN to accommodate all patients, it is acceptable that aspects of their care (eg: genetic testing, risk reduction surgery, endoscopic surveillance) be provided outside of the network, provided that current guidelines are followed, and these key aspects are discussed and documented at the MDT of one of the RDCC's:

· Timing and type of risk reduction surgery
· Endoscopic management of polyps
· Management of extra-intestinal manifestations

The polyposis RDCN has a virtual collaborative MDT meeting on the 2nd Tuesday of every month from 5.30 pm to 6.30 pm. Additional MDTs to discuss cases will be provided by each centre. In the North Thames region, the Polyposis Registry can be contacted by this email: LNWH-tr.smcfic@nhs.net.

RESEARCH OPPORTUNITIES: TRIALS.

1. FIT FOR LYNCH

FIT for Lynch: Research study for patients with a confirmed Lynch syndrome diagnosis between the ages 25-73. This research assess the potential role of faecal immunochemical testing (FIT) as a means of bowel cancer surveillance in people with LS.

People interested in the study are advised to contact the study team. Email: fitforlynchstudy@kcl.ac.uk
For more information visit the website: FIT for Lynch Study - New diagnostic techniques for bowel cancer detection and prevention - St Marks Hospital Foundation Bowel screening study

2. IMMUNOTHERAPY TRIAL 2 - MK-1308A-008A

A phase 2 Multi Arm study to evaluate MK-1308A versus other treatments in participants with MSI High or dMMR Stage IV colorectal cancer.
The trial compares treatment with pembrolizumab alone, to treatment with MK-1308A, MK-4280A or MK-7684A plus pembrolizumab. Patients must have histologically confirmed diagnosis of Stage IV CRC adenocarcinoma (as defined by AJCC version 8) and confirmed dMMR/MSI-H and be more than 18 years of age. There are two groups for the trial.

Eligibility
Group 1: Patients whose cancer has got worse on their treatment. They will be randomised with a 1:1 chance of getting pembrolizumab alone or MK-1308A (which contains both quavonlimab and pembrolizumab).
Group 2: is for those who haven't yet received treatment for their metastatic cancer.In group 2, there are 4 different treatments, as listed below, there is a 1:1:1:1 chance of receiving one of the below:

1. Pembrolizumab alone
2. MK-1308A, which contains quavonlimab (MK-1308) and pembrolizumab
3. MK-4280A, which contains favezelimab (MK-4280) and pembrolizumab
4. MK-7684A, which contains vibostolimab (MK-7684) and pembrolizumab

Hospital Site:
Beaston Cancer Centre Glasgow, Warsgrave Coventry, Cardiff, UCLH
Principal Investigator:
Dr. Kai-Keen Shiu
Contact:
uclh.giresearchclinic@nhs.net with patient name, NHS number, histology report and recent clinic letter.

Useful link:
https://findastudy.uclh.nhs.uk/trial/647677839bdc8e7d875210bb/view

3. PRESCORES STUDY

Preventing Endometrial Cancers: Comparing Risk-Reducing Strategies
Study aims
·To evaluate the quality-of-life of women with Lynch Syndrome
·To determine health-related utility scores of risk-reducing hysterectomy

Contact details:
Dr Sam Oxley: s.oxley@qmul.ac.uk
Prof Ranjit Manchanda: r.manchanda@qmul.ac.uk

4. DETECT-2 STUDY

DETECT-2 study
Eligibility:

Inclusion
Adults diagnosed with colorectal, endometrial cancer and/ or ovarian cancer fulfilling NHS clinical genetic testing criteria.

Exclusion
Patients who have had previous genetic testing for Lynch syndrome or colorectal cancer/ovarian cancer susceptibility genes.
Patients whose family has a known pathogenic variant in one of the following genes being tested.
Unable to provide informed consent.

Hospital Site:
Barts Health BHS Trust
Principal Investigator:
Prof Ranjit Manchanda
More Information:
www.detect-2.co.uk
Contact Email:
bartsctu-detect-2@qmul.ac.uk

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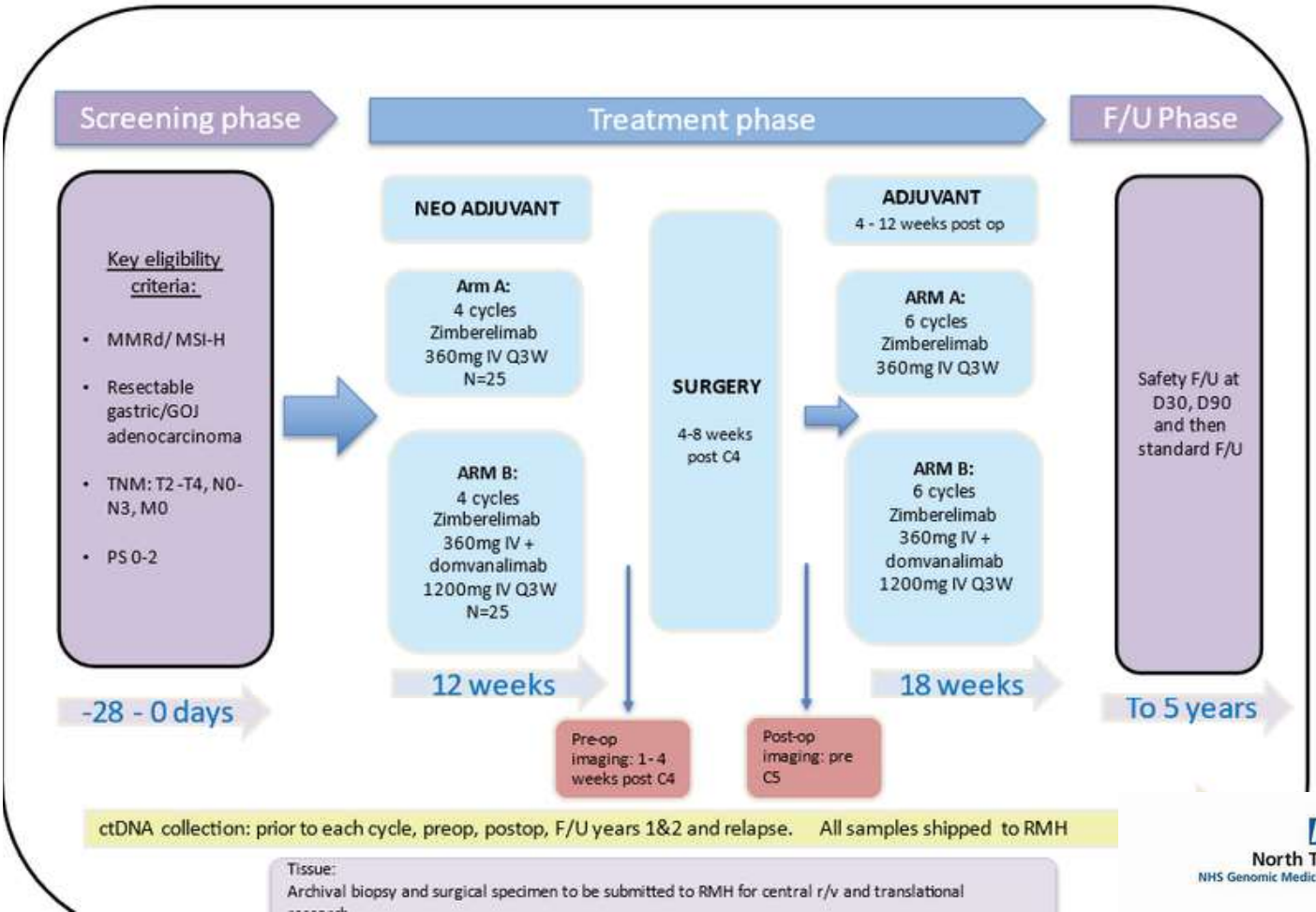
5. ZODIAC

A phase II study of peri-operative anti-PD1 Zimberelimab immunOtherapy +/- Domvanalimab anti-TIGIT therapy in resectable mismatch repair deficient (MMRd) gastric/gastro-oesophageal junctional (GOJ) AdenoCarinoma (ZODIAC)

Key eligibility criteria:
MMRd/MSI-H
Histologically confirmed gastric/GOJ adenocarcinoma
Resectable: Stage II-IIIB (TNM T2-T4, N0-N3, M0)
MDT deemed suitable for surgery and believes R0 resection achievable post neoadjuvant therapy.
PS 0-2



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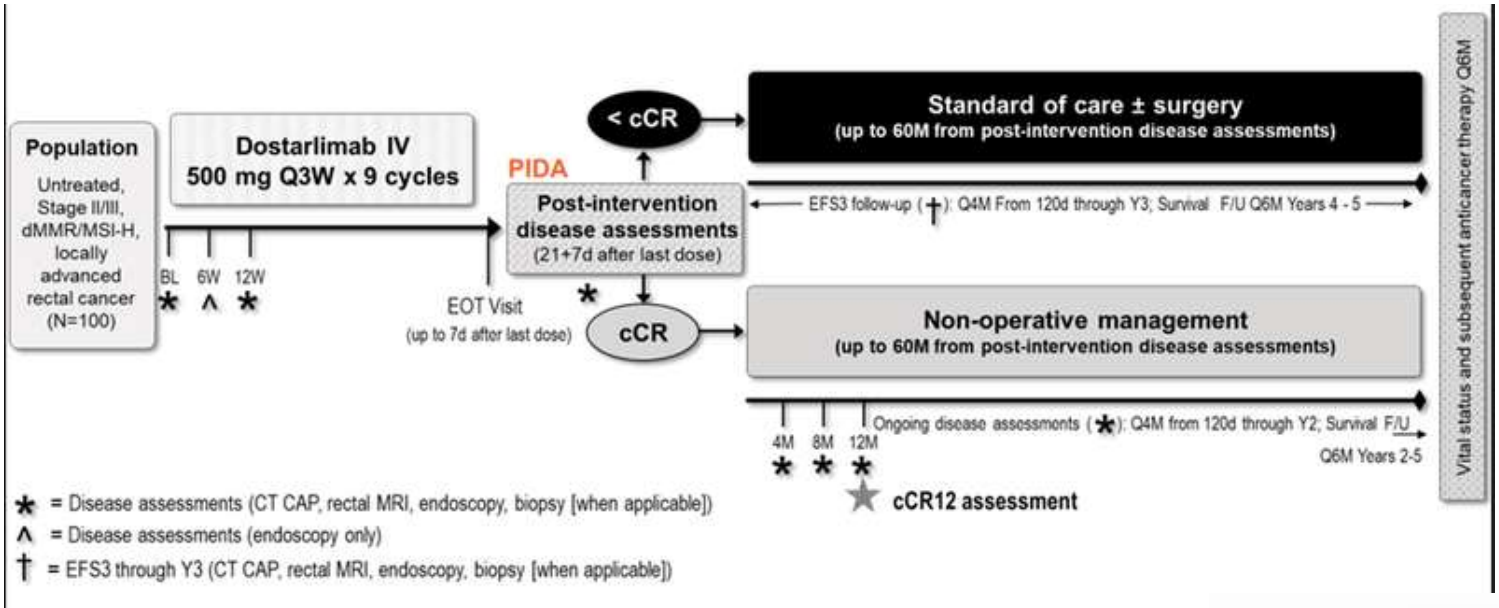
6. AZUR-1

A Phase 2, Single-Arm, Open-Label Study with Dostarlimab Monotherapy in Participants with Untreated Stage II/III dMMR/MSI-H Locally Advanced Rectal Cancer

Key eligibility criteria:
· Untreated histologically confirmed stage II to III (T3-4, N0 or T any, N+) locally advanced rectal cancer with no distant metastatic disease
· Radiologically and endoscopically evaluable disease
· Tumour demonstrating dMMR status assessed by IHC, or MSI-H phenotype, determined either locally or by central reference laboratory
· No symptomatic bowel obstruction
· ECOG PS 0-1

Sponsor:
GSK



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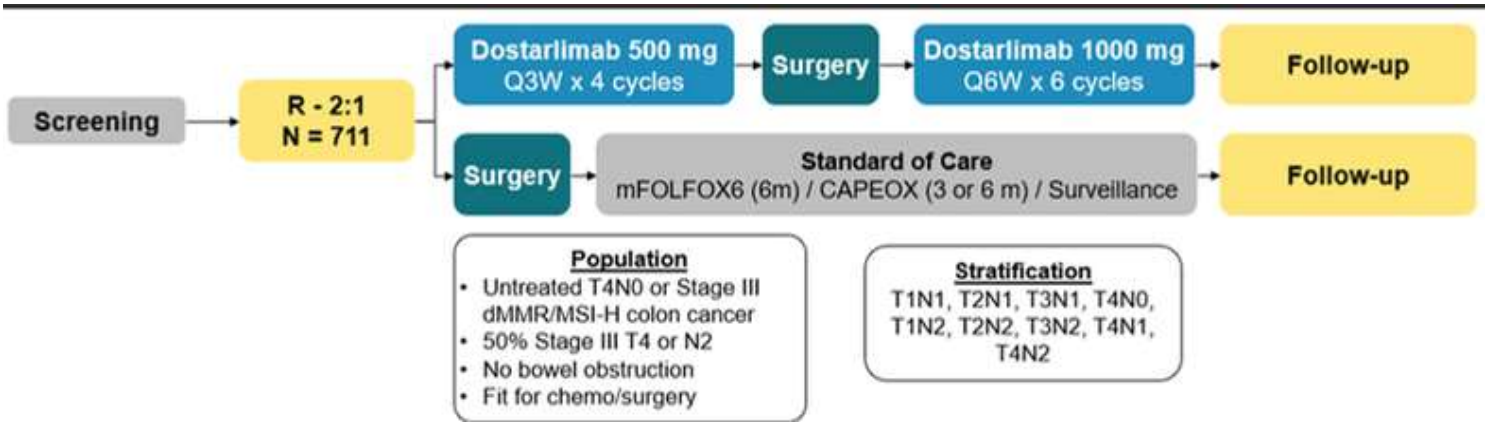
7. AZUR-2

A Phase 3, Open-Label, Randomized Study of Perioperative Dostarlimab Monotherapy versus Standard of Care in Participants with Untreated T4N0 or Stage III dMMR/MSI-H Resectable Colon Cancer

Key eligibility criteria:
- Untreated pathologically confirmed T4N0 or stage III colon adenocarcinoma, with no evidence of metastatic disease
- Radiologically evaluable disease
- Tumour demonstrating dMMR status by IHC or MSI-H phenotype, determined by local or central reference laboratory
- Able to provide fresh or archival (≤ 6 months old) tumour tissue
- No symptomatic bowel obstruction
- Tumour must be amenable to surgery, no contraindications to surgery
- ECOG PS 0-1

Sponsor:
GSK



8. EUROPAC

The EUROPAC Research Study offers pancreatic cancer surveillance to individuals affected by Lynch Syndrome.
If you have been diagnosed with Lynch Syndrome and have at least one family member who has been affected by Pancreatic Cancer, you may be eligible to join the EUROPAC Registry.
As a part of registration, each individual's lifetime risk of developing pancreatic cancer is assessed and the intensity of surveillance is decided.

Participants on the study can expect:

I.) baseline CT
II.) annual EUS (endoscopic ultrasound) and bloods
III.) MRI every three years

The EUROPAC study is an open-ended study that is supported by NHS England, Pancreatic Cancer UK, Cheshire and Merseyside Cancer Alliance and The University of Liverpool.

Further information can be found at https://www.europactrial.com/
Participant Information Sheets can be downloaded from https://www.europactrial.com/familial-pancreatic-cancer